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by

Rhonda Lou Davis

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For the Degree of

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In the Graduate College

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STATEMENT BY AUTHOR

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ABSTRACT

The purpose of this study was to investigate the congruence between hospitalized cancer patients' self-assessments of symptom distress and nurses' assessments of symptom distress in those patients. Using a comparative descriptive design, a convenience sample of 32 nurse-patient pairs completed the modified Symptom Distress Scale. A major finding was the difference between the nurse and patient groups concerning perceptions of symptom distress from mood. Nurses generally rated mood as the most frequent contributor to higher levels of symptom distress, in marked contrast to patients' self-assessments. Patients and nurses also differed in their perceptions of pain, although to a lesser degree than with mood. Nurses' assessments of patients' moods and pain may be influenced by assumptions related to the cancer diagnosis.

CHAPTER ONE

Introduction

According to the National Cancer Institute (NCI), an estimated 1,100,000 new cases of cancer will be diagnosed in 1991. About 514,000 people will die of the disease this year, making it the second leading cause of death in the United States (Boring, 1991). Nevertheless, the past five decades have seen survival rates improve tremendously. In the early 1900s, few cancer patients could anticipate long-term survival. Today, statistics indicate that 40% of newly diagnosed cancer patients will be alive at least five years after initial diagnosis (Cancer Facts and Figures, 1990; Maxwell, 1990).

Improvements in primary therapy and an increased variety of interventions to manage recurrent cancer have contributed to enhanced life expectancy (Maxwell, 1990). At the same time, advances in supportive care technology have allowed patients to tolerate increasingly toxic regimens. Cancer may thus be described as a chronic or protracted illness characterized by intermittent acute episodes (Shils, 1979; Snyder, 1986; Stein, 1982; Varricchio, 1990). However, patients with cancer face continuous adjustments to both the disease and its treatment, either of which may be associated with significant and distressing physical effects (Holmes, 1989).

Nurses and nursing care can assume a vital role in the cancer treatment regimen by focusing on management of symptoms and

symptom distress consequent to therapy. "Cell kill and reduced tumor size are important, but without attention to management of side effects and promotion of functional recovery, the effect is diminished at best and ineffective at worst" (Dorsett, 1990, p. 1156). Thus, in order for patients to gain the maximum therapeutic benefit from treatment, symptom management is a high priority. Nursing care must emphasize continuous systematic assessment to promote the identification and relief of symptoms.

Statement of the Problem

Curative therapies for cancer--surgery, radiotherapy, or chemotherapy--cause damage to nonmalignant healthy tissues and organs and are frequently associated with distressing side effects (Arcand, 1985). Surgery can be traumatic and possibly mutilating (Holmes & Eburn, 1989). In addition to site-specific side effects, fatigue or malaise is common among most individuals during radiotherapy (Hilderly, 1990). Many side effects from chemotherapy result from the drugs' actions on nonmalignant cells with relatively rapid renewal rates, such as those found in the hematopoietic and gastrointestinal systems (Brown & Hogan, 1990).

Not surprisingly, then, the diagnosis of cancer can potentially disrupt an individual's pattern and quality of life, generating profound, distressing concerns (Schneider, 1978). Assessment of symptom distress thus becomes imperative in order for nurses to assist patients in monitoring their level of health or progress, to

determine needs and problems, and to ascertain the effectiveness of various modes of treatment and care (McCorkle, 1987). Additionally, knowing an individual's concerns, difficulties, and available sources of support can enhance the planning and delivery of humanistic personalized nursing care (Schneider, 1978).

However, many of the symptoms associated with malignant disease or with its treatment, such as nausea or anorexia, are not immediately apparent; it is quite possible that nurses would not be aware that such symptoms were present unless patients mentioned them (Holmes & Dickerson, 1987). Providing quality health care depends, to a great extent, on the accuracy of health care providers' perceptions of patients' physical and psychological states (Molzahn & Northcott, 1989). Lilley (1987) believes the very essence of nursing care rests upon nurses' abilities to perceive and understand cues about their patient's comfort level. However, there is a natural inclination for health care professionals, who are in a state of good health, to make assumptions about the level of distress a particular symptom might cause (Lough, Lindsey, Shinn, & Stotts, 1987). For optimum symptom management, nurses must accurately assess the distress produced by patients' symptoms in order to implement appropriate interventions and evaluate their effectiveness.

Purpose

If the nursing process is an ongoing, dynamic, interpersonal process dependent on the changing behaviors of patient and nurse,

then the nurse must be continuously observing and measuring the changes. An understanding of patient and nurse perceptions is essential to facilitate the success of the interpersonal relationship between patient and nurse as well as the nursing care given when some interference occurs in the life cycle. The purpose of this study was to investigate the congruence between hospitalized cancer patients' self-assessments of symptom distress and nurses' assessments of symptom distress in those patients.

Research Questions

1. What are the self-assessments of symptom distress as perceived by hospitalized patients with cancer?
2. What is the assessment of symptom distress as perceived by nurses caring for those hospitalized patients?
3. How do assessments of symptom distress as perceived by hospitalized cancer patients compare with assessments of symptom distress as perceived by their nurses?

Conceptual Definitions

Perception is "a process of organizing, interpreting, and transforming information from sense data and memory" (King, 1981, p. 24). It represents one's image of reality and influences behavior (King, 1981).

Symptom distress is "the degree of discomfort reported by the patient in relation to his/her perception of the symptoms being experienced" (McCorkle & Young, 1978, p. 373).

Significance of the Problem

In cancer, the individual cell ceases to function normally and mechanisms regulating growth and proliferation are disturbed. Cellular disorganization results in aberrant tissue growth patterns; signs and symptoms characterize the clinical expression of subsequent tumor formation. Normal tissues may also be adversely affected by treatment regimens intended to eradicate transformed cells. Consequently, nurses become actively involved in detecting changes in patient status, with the emphasis on maintaining the individual at the highest level of health possible. Although growth patterns of individual cells cannot be observed clinically, patients' responses to those growth patterns can be monitored on the basis of related signs and symptoms (Bonfiglio & Terry, 1983; Longman & Rogers, 1984). Early detection of changes in patients' responses may make a difference in their ability to withstand treatment regimens and may even play a significant role in how long they live (Kukull, McCorkle, & Driever, 1986; Longman & Rogers, 1984).

Often it is unclear whether the disease, its treatment, or the chronicity of the illness is the primary cause of a given symptom (Donovan, 1986). Irregardless of the cause, symptoms can result in significant distress, decreasing patients' abilities to perform

activities of daily living. This symptom distress is believed to have a marked impact on quality of life (Ehlke, 1988; Holmes & Dickerson, 1987; Holmes & Eburn, 1989; Strauman, 1986; Watson, Rhodes, & Germino, 1987).

Nursing care of individuals with cancer necessitates not only helping patients adjust to permanent changes in body image, function, and appearance, but also helping them cope with the many distressing physical effects associated with the disease and its treatment (Holmes & Eburn, 1989; Padilla & Grant, 1985; Snyder, 1986). In a 1988 Oncology Nursing Society survey, respondents identified symptom management (side effects of disease/treatment) as one of the top five research priorities (Funkhouser & Grant, 1989).

While physicians are primarily concerned with symptom occurrence in the diagnosis and treatment of disease, nurses are often responsible for assisting patients with monitoring and relieving their symptoms (McCorkle, 1987). In fact, King (1971) stated objective assessment of functional abilities and disabilities of individuals is one of the primary responsibilities of nurses. The concept of symptom distress is therefore important in nursing and generally considered to be within the realm of nursing care (Graham & Longman, 1987; McCorkle, 1987; Rhodes & Watson, 1987).

Symptom distress can have a significant impact on the final treatment outcome relative to its effect on patient compliance and on the ability of the physician to administer the treatment according

to an optimal schedule. Symptoms such as nausea or fatigue can be sufficiently distressing to patients that they choose to discontinue therapy (Rhodes & Watson, 1987; Strauman, 1986). Alternatively, severe side effects may prompt patients to request reductions in treatment or to resort to unproven, quack remedies (Nerenz, Leventhal, & Love, 1982). Nurses who recognize and respond to patients' priorities in symptom management promote the patient's sense of control in the situation, effectively decreasing feelings of helplessness (Donovan, 1986).

Identifying symptoms and assessing their effects, then, are not only fundamental to symptom management, but can also provide important information to help patients function at an optimal level (Ehlke, 1988; Strauman, 1986). Assessing the severity of symptom distress, however, must incorporate patients' views of their condition. Quality of life is increasingly recognized as highly dependent on each individual's perception of it (Graham & Longman, 1987; Holmes & Eburn, 1989).

Summary

Advanced treatment modalities for cancer have contributed to significantly improved survival rates for this disease. Accordingly, cancer is increasingly viewed as a chronic illness and attention has subsequently focused on control of the disease and its symptoms. The various effects of the disease process and its treatment can contribute to symptom distress, adversely affecting quality of life.

How effectively nurses are able to help patients manage their symptoms may well influence their ability to cope with cancer and adjust to any necessary changes in lifestyle. However, assessing the severity of symptom distress must incorporate the patients' perceptions of their condition.

CHAPTER TWO

Conceptual Framework and Review of the Literature

The purpose of this chapter is to describe a conceptual framework for the study and to report on literature relevant to the constructs, the concepts, and the operational indicator. King's Open Systems Framework was chosen to guide this study and definitions of the constructs--patient, nurse, and health-illness--reflect this perspective. Following a discussion of the constructs, the concepts of perception, symptoms of cancer treatment, and symptom distress are presented. A description of the operational indicator, the modified Symptom Distress Scale, concludes the chapter.

Conceptual Framework

King's conceptual framework consists of three dynamic interacting systems (Fawcett, 1989; Riehl-Sisca, 1989). The individual is a personal system who coexists with other personal systems in the environment. Individuals form interpersonal systems, such as dyads, triads, or larger groups. Thus, the personal systems of patients and nurses comprise subsystems within interpersonal systems (Figure 1). Ultimately, interpersonal systems are experienced in the context of social systems, such as family, school, industry, and other organizations (Chinn & Kramer, 1991; Gonot, 1989; Riehl-Sisca, 1989).

The nursing focus is the human being in the system context and the goal is health. "Health implies helping people in groups attain.

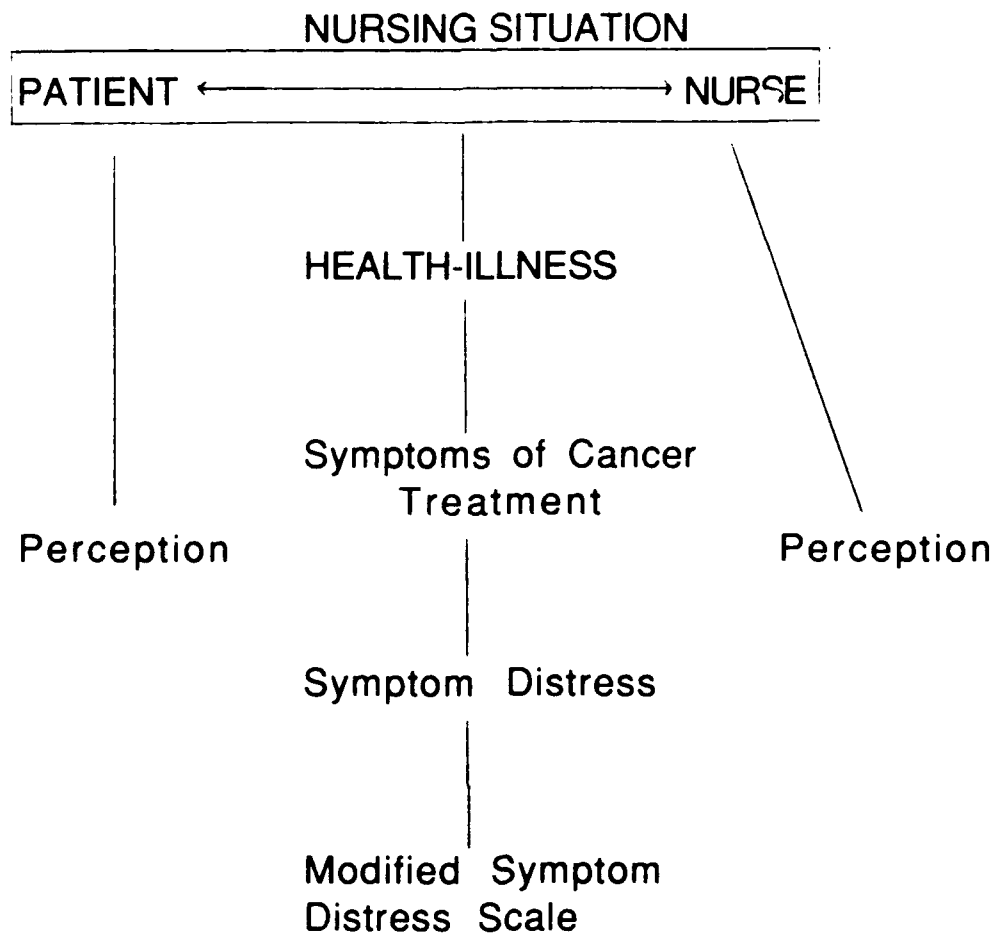


Figure 1. Conceptual Framework: Adaptation of King's Open Systems Framework to Nurses' and Cancer Patients' Perceptions of Symptom Distress

maintain, and restore health, live with chronic illness or disability, or die with dignity" (Chinn & Kramer, 1991, p. 185). Thus, nurses, in the performance of their roles and responsibilities, interact with and assist individuals and groups to cope with potentially stressful situations relative to health and illness and to adjust, if necessary, to changes in activities of daily living (Fawcett, 1989; King, 1968, 1971, 1976).

The patient with cancer confronts one of the greatest stress situations imaginable. Far from being a single traumatic experience, the impact of cancer precipitates a series of crises. These include fear of symptom meaning, interruptions of life experiences, effects of treatment, and the possibility or actuality of recurrence (Donovan, 1978). In assisting patients to cope with cancer, the nursing role is frequently one of helping to manage side effects of therapy and facilitating adjustment to permanent changes in body image, function, and appearance (Padilla & Grant, 1985).

To this end, the nurse and the patient participate in a dynamic, ongoing interpersonal process and together are viewed as a system, each affecting the behavior of the other and both being affected by factors within the situation (Daubenmire & King, 1973). When the nurse and patient perceive each other and the situation, they identify specific goals, problems, or concerns and determine means to goal achievement through purposeful communication (Fawcett, 1989; Gonot, 1989; Riehl-Sisca, 1989). This interaction between nurse and patient is thus a reciprocal process, with a continual

giving and receiving of information and feedback. (Figure 1) (King, 1986).

An individual's decision to adhere to a cancer treatment regimen may be significantly affected by the ability to tolerate noxious side effects and the degree of interference with activities. Nurses can exert an impact on patients' participation in the treatment regimen by prescribing and supervising a plan of care. However, patients as well as nurses bring functioning values and beliefs to the nursing situation; these in turn shape behavior and actions. If mutual goals are set but only the nurse decides how goals are to be achieved, the patient may have difficulty adhering to the treatment plan (Carnevali & Reiner, 1990; Disch & McEvoy, 1990).

The objective of interaction in the nursing process is transaction, a goal-directed behavior that reduces tension or stress in a situation. If perceptual accuracy is present in nurse-patient interactions, transactions will occur and lead to goal attainment, satisfaction, effective care, and enhanced growth and development (Chinn & Kramer, 1991; Gonot, 1989; King, 1986).

Constructs

Patient

The patient is a unique total system whose permeable boundaries permit an exchange of matter, energy, and information in interaction with the environment. Patients, characterized as social

beings who are rational and sentient, process selective inputs from the environment through the senses. In the process of human interactions, individual patients react to persons, events, and objects in the environment in terms of their perceptions, expectations, needs, values and goals (Fawcett, 1989; Gonot, 1989; King, 1981).

Thus, a number of factors influence the behavior of people with a diagnosis of cancer. These include perception of the illness and the course of therapy, the character of the cancer, and the sense of role identity and acceptance of role expectations in relation to the cancer (Disch & McEvoy, 1990).

Nurse

Nurses are key figures in health care delivery. King (1976) stated they promote health, prevent disease, and manage patient care in partnership with physicians, social workers, and allied health professionals. They also "cooperate with physicians, families, and others to coordinate plans of health care" (King, 1976, p. 52).

Nursing is described as a helping profession which cares for individuals and groups who are ill and hospitalized, those who have chronic diseases and require rehabilitation, and those who require guidance for health maintenance. People seek help from nurses when they cannot perform their usual daily activities. Thus, patients and nurses establish relationships in nursing situations (Figure 1) to

cope with health states and to adjust to any necessary changes in activities of daily living (Daubenmire & King, 1973; King, 1976, 1981).

Cancer nursing occurs in a variety of settings, including the hospital setting, the outpatient setting, and the home setting. The work of oncology nurses in these various settings may relate to prevention of cancer, diagnosis and treatment of cancer, and rehabilitative and supportive care of cancer patients (Sarna, 1985). Whatever the setting, the goal of oncology nursing is to assist patients and families to live with the chronic disease of cancer (Bouchard-Kurtz, 1981).

Health-Illness

Defining health as a dynamic state in the life cycle, King (1971) explained this implies an optimum use of resources to continually adapt to stresses in the internal and external environment, thus achieving maximum potential for daily living. Illness was defined as a deviation from normal and seen as an imbalance in a person's biological structure or psychological make-up (King, 1981).

Cancer, like all chronic illness, evolves over a considerable period of time. Thus, cancer patients are faced with a continuing condition characterized by a series of crises of varying intensity and duration. Compounding these stressors is the fact that cancer treatment is frequently complex, often extended, and can potentially

damage physical, mental, or social functioning (Mages & Mendelsohn, 1979; McGee, 1990)

The goal of nursing and the nursing situation (Figure 1) is health. Given that cancer is a disturbance in the life cycle, nurses' actions are goal directed to help patients adapt to the attendant stressors and achieve maximum potential for daily living. The chronicity of cancer implies that an individual's health is a dynamic state in which change is a constant and ongoing process (King, 1971; Riehl-Sisca, 1989).

Concepts

Perception

A major component in human interactions, "perception is an awareness of objects, persons, and situations" (King, 1971, p. 87). In the process of perception, information from sense data and memory is organized, interpreted, and transformed. The perceptual process also encompasses human transactions with the environment, thus giving meaning to experience, rendering an individual image of reality, and influencing behavior (King, 1981). This implies that both environmental stimuli and an internal process are sufficient and necessary conditions for perception to occur (Bunting, 1988).

Although perception is universal, or experienced by all, it is unique to each human being. It represents a subjective, or personal, experience so that individuals view the world from their own perspective. Thus, each person involved in a given situation will

experience it in a unique manner. Based on the information available, each will act as a result of personal perceptions of individuals, objects, or events (Fawcett, 1989, George, 1990, King, 1968).

In King's conceptual framework, perception is a vital component influencing the interaction process between patient and nurse (Figure 1) (Bunting, 1988; George, 1990; Riehl-Sisca, 1989). Patients undergoing cancer treatment perceive a variety of physical, psychological, and psychosocial changes that influence their lives and daily habits (Fernsler, 1986). They relate to the environment through their perceptions, and nurses and their communications are part of that environment. Nurses must therefore negotiate with patients' perceptions of the world, rather than with some objective reality (Bunting, 1988). In the process, they infer thoughts and feelings from what patients say or do or how they speak and act. These perceptions lead to judgments and to action by the nurse. Patient perceptions lead simultaneously to judgments and then to action by the patient, thus contributing to a continuous dynamic process (King, 1971).

Variations in perception occur from one individual to another because each has different backgrounds of knowledge, skills, abilities, needs, values, and goals (Riehl-Sisca, 1989). Past experiences, self-concept, socioeconomic status, biological inheritance, and education also influence perception (King, 1971). Other factors, such as race, ethnicity and nationality, indicate

cultural orientation and are considered to be important determinants of perceptions (Molzahn & Northcott, 1989).

Davitz and Pendleton (1969) were among the first to investigate factors influencing nurses' perceptions of patient suffering. In four separate studies, they considered different aspects of the same issue. The first study sought to determine if the cultural background of nurses ($n = 130$) influenced their perceptions. The second study attempted to ascertain if nurses' inferences ($n = 116$) differed according to their clinical specialty. The third study focused on how patient diagnosis related to the degree of suffering inferred and questioned whether the nurses ($n = 94$) had acquired a particular set of perceptions regarding the degree to which a patient suffers as a consequence of a given illness. The final study examined nurses' inferences of suffering ($n = 67$) from the point of view of specific patient characteristics.

None of the studies conducted by Davitz and Pendleton (1969) reported instrument reliability and validity. An essentially similar instrument was adapted to the specific objective of each study. Each of the four instruments consisted of brief patient descriptions and the nurses were asked to infer the degree of suffering experienced by each patient. Thus, nurses were limited to inferring from written descriptions and were unable to respond to the patient actions observable in a real situation.

Findings of these studies suggested that inferences of suffering differ according to the cultural background of the nurse

and according to patient diagnosis, age, and socioeconomic background. No differences in inferences were found in relation to clinical specialty of the nurse or sex of the patient (Davitz & Pendleton, 1969).

Mason (1981) also sought to identify factors influencing nurses' inferences of patient suffering, defined as physical pain or discomfort and/or psychological distress. She used a questionnaire consisting of patient situations with two scales for nurses ($n = 161$) to rate the degree of physical pain and psychological distress in each situation. Reported instrument reliability was .96 for both physical pain and psychological distress. The test-retest correlation was .89 for physical pain and .87 for psychological distress. One patient factor, age group, and several nursing factors, including educational preparation, activity status (full-time/part-time), position held, place of employment, and length of professional nursing experience, were selected for study.

While the length of professional experience was not a statistically significant factor in inferences of psychological distress, nurses with less than one year of professional nursing experience and nurses with 6-10 years of experience differed in their inferences of physical suffering at a significance level of $p < .05$ using Scheffe Confidence Intervals. Mason (1981) found that nurses with the lesser amount of experience inferred the greatest degree of physical suffering.

Patient age was also a statistically significant factor in influencing the nurses' inferences of patient suffering. A greater amount of physical pain and discomfort was inferred in children than in patients over 65 years of age ($p < .05$). Psychological distress was inferred to the greatest degree in patients 30-45 years of age ($p < .001$). The nurse's age, educational preparation, activity status, and position were not found to influence inferences of patient suffering, either physical or psychological (Mason, 1981).

In one of the first studies comparing perceptions between two groups, Jennings and Muhlenkamp (1981) sought to determine whether there was congruence between caregiver evaluations of oncology patients' anxiety, hostility, and depression, and those patients' self-reported levels of the three affective states. They also tested a control hypothesis by evaluating the patients' levels of denial.

Terminally ill hospitalized oncology patients ($n = 28$) completed the "Today" form of the Multiple Adjective Affect Check List (MAACL), which measures levels of anxiety, hostility, and depression, and the Digit Span Backwards Test (DSBT), which the investigators used to evaluate level of denial. Caregivers ($n = 28$), each familiar with the care of one of the patients, were instructed to complete the MAACL as they believed the patient would fill it out.

The MAACL had established construct validity, according to Jennings and Muhlenkamp (1981). Additionally, they stated the test-retest reliability of the "Today" form of the MAACL had been

previously reported as low, suggesting sensitivity of the instrument to daily mood fluctuation. In a discussion of the DSBT, Jennings and Muhlenkamp cited previous studies which reported high test-retest reliability when it was used to measure denial as a specific coping strategy under stress.

Findings in this study (Jennings & Muhlenkamp, 1981) revealed a statistically significant discrepancy for each affective state: anxiety ($E [1, 54] = 15.1; p < .001$), depression ($E [1, 54] = 13.6; p < .001$), and hostility ($E [1, 54] = 6.8; p < .02$). In other words, the caregiver rated the patient as feeling considerably worse than the patient reported feeling. Denial was ruled out as affecting patients' self-reported states.

In another study, 25 elderly patients on a short-stay geriatric ward and their nurses completed a hospital stress scale about the patients' perceived stresses during the first (occasion 1) and third (occasion 2) weeks of hospitalization. The scale consisted of 16 items chosen from a pool of 31 stress items previously discussed with patients. Validity and reliability of the scale were not reported. Although Davies and Peters (1983) found a strong concordance between what the patient group and the nurse group thought patients found stressful, they attributed this to both groups sharing common stereotypes about the hospital situation. When individual nurses and their patients were compared, there was no statistically significant relation between nurses' and patients' ratings of the overall stress being experienced by the patients ($r =$

-.09 for occasion 1; $r = +.03$ for occasion 2). In other words, nurses' ratings did not reflect the degree of stress reported by patients; patients reporting high or low levels of stress were not distinguished as such by their nurses.

Carr and Powers (1986) also assessed the concordance between patient ($n = 30$) and nurse ($n = 18$) perceptions of stressors, this time in patients recovering without complications from coronary bypass surgery. The Likert scale developed by the investigators to assess the severity of stressors was reported to have theoretical and empirical content validity. Addressing internal consistency of the scale, the authors reported alpha coefficients of .92 for the patient sample and .88 for the nurse sample.

Patients completed the stressor scale in terms of their personal experiences with coronary bypass surgery while nurses rated the items based on their general experience with coronary bypass patients. The nurses generally rated all items as significantly more stressful for coronary bypass patients than did the patients themselves ($F(1, 92) = 52.9, p < .0005$). Carr and Powers (1986) attributed this to the idiosyncratic perspective used by the patients in deciding on their stressfulness ratings, in contrast to the broader basis of comparison used by the nurses. They speculated that findings might have differed had the nurses been asked to rate specific patients under their care at that point in time.

A similar study by Cochran and Ganong (1989) was designed to compare intensive care unit (ICU) nurses' ($n = 23$) and patients' ($n = 20$) perceptions of stressful factors for patients in the ICU. One to two days following transfer from an ICU, patients completed the Intensive Care Unit Environmental Stressor Scale (ICUESS), a Likert-type questionnaire designed to measure the stressfulness of items commonly occurring in the ICU environment. Nurses were asked to complete the same questionnaire as they believed an ICU patient would complete it.

The ICUESS (Cochran & Ganong, 1989) was an adaptation of another tool previously examined for face and content validity. Additionally, use of the instrument in this study differed from previous studies in which only ICU patients had been asked to rank environmental stressors and in which Q-sort cards were used to rank the stressors. Instrument reliability was not addressed.

Cochran and Ganong (1989) reported that nurses consistently rated the items on the ICUESS as being significantly more stressful (p ranged from .01 to .0001) than did the patients. While patients appeared to be most concerned with items that directly related to physical stressors, nurses rated psychosocial stressors as being relatively more stressful.

Addressing stress in the cancer patient, Fernsler (1986) postulated that disparities between patients' and nurses' perceptions of the chemotherapy experience might result in increased stress during the treatment period. She reported a

descriptive study designed to compare patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Thirty outpatients in a hematology oncology clinic and their assigned nurses ($n = 5$) participated in the study.

Fernsler (1986) constructed two open-ended semistructured interview schedules, one for nurses and one for patients. Wording of the two interview schedules was identical except that nurses were instructed to respond in relation to patient needs at the time of chemotherapy administration. The investigator reported adequate stability in use of the interview schedule. Experts on a self-care nursing model were consulted to establish content validity of the interview question as well as interrater reliability in classifying responses.

Fernsler (1986) found that patients generally perceived more self-care deficits than did nurses in the categories that included problems with physical side effects of therapy, while nurses perceived slightly more deficits than did patients in relation to the categories that included psychosocial problems. However, these results may be influenced by the small sample of nurses included in the study. Although responses from each of the patients reflected 30 different perceptions, the responses from each nurse reflected perceptions of several patients and may have been affected by nonindependence of observations. In addition, since nurses were interviewed more than one time, sensitization to the research

methodology may have influenced the nature and quantity of nurses' responses over time.

Lilley (1987) investigated the relationship between registered nurses' perceptions ($n = 15$) and uterine cancer patients' ($n = 15$) perceptions of human need fulfillment alterations. While the findings of this study indicated that the registered nurse sample perceived human need fulfillment alterations similarly to the patient sample, Lilley noted two important trends. Nurses as a group tended to rank physiological needs as of greatest importance for patients, while the patients as a group rated emotional, spiritual, and psychosocial needs higher.

Symptoms of Cancer Treatment

Although symptoms have been defined as "distinctive features interpretive of a disease category used to diagnose a patient's condition" (Rhodes & Watson, 1987, p. 242) and have often included signs or objective clinical manifestations, symptoms are subjective phenomena and stressors perceptible only to the patient. They are regarded by the individual as an indication or characteristic of a condition departing from normal function, sensation, or appearance (Rhodes & Watson, 1987). Symptoms of cancer treatment, then, represent a deviation from normal and an indication of illness (Figure 1) (King, 1981).

Because physical symptoms or sensations are private, it is difficult to objectively measure the causes responsible for symptom

occurrence. As phenomena experienced by a person and not directly observable by another, they may be perceived and verified only by the person experiencing the event. Thus, symptoms such as nausea, fatigue, and pain only become known through the report of the person being assessed (Rhodes & Watson, 1987).

Pain. In cancer, acute pain may be experienced as a result of surgery. Chronic pain is intermittent or constant discomfort that persists beyond the resolution of an acute process and may occur as a result of scarring from surgery or radiation therapy. Chronic pain may also signal disease progression when the growth of the malignancy intrudes on normal tissues. For example, cancer patients may experience pain when tumor infiltrates or compresses nerves, blood vessels, or lymphatic channels. Other causes of chronic pain include disruption of nerve pathways due to pathologic fractures, obstruction of hollow structures such as the intestine or ureters, and inflammation, infection, or necrosis of tissue affected by neoplastic growth. Finally, tumor infiltration or distention of tissues which are pain-sensitive, such as fascia or periosteum, or nonelastic, such as scar tissue, may cause pain (Burns, 1982; Yasko, 1983).

Decreased mobility. Since patients who have severe chronic pain often avoid movement, particularly in the area of the body which is painful, mobility may become impaired. Immobility may increase as the pain causes depression, lassitude, fatigue, loss of sleep, and further muscular weakness (Burns, 1982; Yasko, 1983).

Fatigue. Acute and/or chronic fatigue may result not only from cancer and side effects of cancer treatment, but also from the psychological distress induced by a potentially life-threatening diagnosis. Direct tissue damage as well as effects of anesthesia and analgesics cause patients undergoing surgical procedures to experience fatigue which may persist up to six months following surgery. Fatigue is also the most prevalent side effect experienced by patients receiving chemotherapy and is one of the only systemic side effects of local radiation treatment; accumulation of waste products from tumor destruction may be a factor (Nail, 1990; Yasko, 1983)).

Fatigue may result from anemia when tumor infiltrates the bone marrow and destroys erythrocytes, or when bleeding occurs at the tumor site. Anemia may also be caused when chemotherapy and radiation therapy contribute to bone marrow depression and decreased production of erythrocytes and platelets.

Protein-calorie malnutrition plays a role in fatigue and has many causes. Active tumor growth is associated with a hypermetabolic state and competition of the tumor with the body for protein and calories. Patients may also experience an inadequate intake of protein, calories, vitamins, and minerals due to the pathology of the cancer or the toxic effects of cancer treatment (Yasko, 1983).

Patients with fatigue often complain that it changes their appearance and interferes with their concentration and thought

processes. Effects of fatigue may be manifested as difficulty in attending to and understanding instructions, irritability, inadequate short-term memory, and difficulty in organizing information provided to caregivers (Nail, 1990; Nail & King, 1987).

Sleep disturbance. Even as energy is required to deal with symptoms or side effects, individuals with cancer may experience disruption in their usual restorative activities when nausea, pain, or urinary frequency interfere with sleep and rest (Nail, 1990). Hospitalization itself can contribute to anxiety and loss of sleep. The diagnosis of cancer can cause stress and varying degrees of anxiety and depression, with consequent effects on sleep patterns (Thomas 1987).

Mood disturbance. Depression has been identified as one of the most common responses to cancer and is seen as a ubiquitous response to actual or potential loss. Cancer represents a potential loss of not only life, but also body parts and functions, roles, and relationships (Clark, 1990).

Change in body image. Changes in appearance, disabilities, and loss of function resulting from cancer and its treatment often cause a change in body image and can negatively affect a patient's self-esteem. Side effects of treatment may result in distressing symptoms, such as alopecia, pain, nausea, vomiting, diarrhea, weakness, fatigue, muscle atrophy, and neurologic changes, that interfere with the patient's body image. Patients may consequently

feel worthless, physically unattractive or even repulsive, and unable to be valued or loved (Dudas, 1990).

Nausea and vomiting. "Nausea and vomiting, often accompanied by anorexia, are among the most frequent symptoms associated with cancer and cancer treatment" (Grant, 1987, p. 277). One of the causes of nausea and vomiting in the cancer patient is stimulation of the chemoreceptor trigger zone (CTZ) by tumor byproducts, either as a result of tumor growth or as a consequence of cell destruction from chemotherapy and radiation therapy. Nausea may also result because of the direct effect of radiation on the epithelial cells lining the esophagus, stomach, and/or intestines (Hilderly, 1990; Yasko, 1983). Many chemotherapeutic agents stimulate the CTZ: nausea and vomiting effects may even be increased with high dose bolus intravenous administration and when agents are given in combination (Yasko, 1983).

Anorexia. The nausea and vomiting associated with chemotherapeutic agents are among various factors contributing to loss of appetite in cancer: any interest in food may be eliminated for fear of the consequences. Metabolic alterations evoked by the tumor may also cause appetite suppression by creating in the hypothalamus a false interpretation of satiety. Chemotherapy and radiation therapy may affect the oral and esophageal mucosa, resulting in dysphagia because of inflammation and ulceration. Any physical discomfort may depress appetite and lead to reduced food intake. Taste changes, as well as hospitalization, may lead to

altered dietary habits and a disinterest in food. Finally, because eating requires the expenditure of energy, immobility or fatigue may lead to a loss of appetite or an inability to perform the motor functions necessary for eating (Szeluga, Groenwald, & Sullivan, 1990; Yasko, 1983).

Change in bowel habits. Other gastrointestinal effects of cancer treatment include changes in bowel habits. Surgery can disrupt the usual pattern of gastrointestinal motility or absorption, resulting in diarrhea. Chemotherapy and radiation therapy, either externally to the abdominal area or as an internal source in the uterus, cervix, or vagina, may destroy actively dividing epithelial cells, resulting in intestinal mucosal atrophy, shortening or denuding of the villi, and consequent diarrhea. Patients receiving high osmolarity supplemental feedings or experiencing anxiety or increased stress may also have diarrhea (Burns, 1982; Szeluga, Groenwald, & Sullivan, 1990; Yasko, 1983).

Conversely, anxiety or depression can result in constipation. Decreased peristalsis is also a side effect of several pharmacologic agents, especially the vinca alkaloids and narcotics. Other factors that contribute to constipation include dehydration, decreased mobility, inadequate dietary fiber intake, and changes in the usual patterns of elimination. Fatigue and weakness are often associated with decreased mobility and may potentiate constipation (Burns, 1982; Yasko, 1983).

Symptom Distress

According to Rhodes and Watson (1987), perception of distress is the ability of the individual to be cognizant of and to discern the amount of upset, strain, or physical or mental anguish accompanying an experienced symptom. The degree of distress experienced by a patient is not observable; it can only be conjectured by another human being (Rhodes, Watson, & Johnson, 1984). Only the individual can perceive, verify, and rate the severity or harshness of symptoms, which includes the amount and degree of discomfort (Rhodes & Watson, 1987).

One of the first to investigate the concept of symptom distress, Hinton (1963) compared 102 dying patients with a corresponding control group of 102 nonterminal but seriously ill patients. Terminal patients included those with cancer, heart failure, or renal disease. Nonterminal patients had problems such as intestinal obstruction. He sought to assess the amount of mental and physical distress experienced in a terminal illness, to investigate relationships between the distress experienced and features of the patients' illness or personal life, and to observe for any alteration in the distress as death approached. Physical distress was defined as "physical discomfort of such a degree that it distressed the patient and was severe enough to warrant treatment directed towards its relief" (Hinton, 1963, p. 2). Hinton considered pain, dyspnea, nausea or vomiting, malaise, or persistent cough as types of physical distress and graded them as absent.

relieved, unrelieved and inconstant, or unrelieved and constant. Results of the study included the finding that dying patients had a significantly higher incidence of unrelieved physical distress ($p < 0.01$).

Several years later, Schneider (1978) studied the personal concerns and problems identified by oncology patients in an outpatient setting. Using a series of open-ended questions related to activities and feelings that people experience on a day-to-day basis, 26 patients from the medical oncology and radiation oncology clinics were interviewed. Eighty-four percent of the medical oncology patients named a side effect of treatment or a current physical inconvenience, such as tiredness, pain, or diarrhea, as causing the most difficulty during their illness. In contrast, only 28% of radiation oncology patients named a physical inconvenience or side effect of therapy.

McCorkle and Quint-Benoliel (1981, 1983) studied the level of symptom distress, current concerns, and mood disturbance in both newly diagnosed lung cancer ($n = 56$) and newly diagnosed heart attack ($n = 65$) patients. The McCorkle and Young (1978) Symptom Distress Scale was modified to include additional items reflective of symptoms lung cancer patients might experience. The investigators referred to previous studies (McCorkle & Young, 1978; Schneider, 1978) for support of instrument reliability and validity.

Mood disturbance was measured using the Profile of Mood States, a Likert-format scale that measures perceptions of feelings

or affect. It was judged valid and reliable on the basis of six factor analytic replications. McCorkle and Quint-Benoliel (1983) also reported that in addition to predictive and construct validity, highly satisfactory stability and test-retest reliabilities had been demonstrated previously with the scale.

Results of data collection revealed that cancer patients experienced more symptom distress of all kinds than heart attack patients. Findings indicated that although individual heart attack patients may have experienced more distress than individual cancer patients, every type of symptom assessed was worse, on average, for the cancer group ($F(1, 119) = 39.7; p < .001$). Fatigue was the most distressing symptom for both groups of patients. Cancer patients also identified pain frequency, cough, lack of appetite and insomnia as troublesome symptoms.

Symptom distress was found to contribute to increased mood disturbance for cancer patients on two measurement occasions ($r = .56, p = .01$ for occasion 1; $r = .60, p = .01$ for occasion 2) and McCorkle and Quint-Benoliel (1983) posited that cancer patients were more disturbed because of their increased symptoms. They concluded that the most striking difference between the two groups was the greater degree of symptom distress and pain experienced by the cancer patients.

Nerenz, Leventhal, and Love (1982) were interested in discovering factors associated with emotional distress during cancer treatment and subsequent decisions by patients to delay.

reduce, or terminate treatment. They conducted interviews with 61 patients receiving chemotherapy for malignant lymphoma. The patients also completed a detailed questionnaire about treatment side effects which included a self-report scale for rating emotional distress. Instrument reliability and validity were not addressed.

Results of the study indicated the number of side effects experienced was positively correlated with distress ($r = 0.55$, $p < .01$). Interestingly, distress was associated more with vague, diffuse side effects such as tiredness and pain than with acute, specific side effects such as nausea and vomiting. Additionally, patients who reported either unsuccessful attempts to cope with side effects or no attempts at all had greater distress than those whose responses indicated successful coping (Nerenz, Leventhal, & Love, 1982).

Kukull, McCorkle, and Drier (1986) interviewed 53 patients with inoperable lung cancer one and two months after their diagnosis to obtain data on their level of symptom distress, as well as on selected psychosocial and demographic variables. McCorkle and Young's (1978) Symptom Distress Scale, expanded to 13 items (McCorkle & Quint-Benoliel, 1983), was one of the instruments used for data collection. Internal consistency using Cronbach's alpha was .79 for the scale.

The patients were followed for about four years, at which time 45 had died of lung cancer, two had died of other causes, four remained alive, and two were lost to follow-up. From among the

variables considered, the patients' postdiagnosis symptom distress score was found to be the most important predictor of survival after adjusting for age, functional status, and personality traits. Kukull, McCorkle, and Drier (1986) concluded that the magnitude of symptoms that patients report soon after diagnosis may influence how long they live. On the other hand, the association between survival and symptom distress may also reflect an association with the patient's histologic type, with the frequency and dosage of radiation, or with other variables not included in the analysis. The authors also questioned whether the data reflected not only a particular symptom's objective existence but also the psychological impact or integration of symptoms.

Knobf (1986) conducted an exploratory study with 78 subjects to quantify the degree of physical and psychologic distress experienced by breast cancer patients treated with adjuvant chemotherapy. Physical distress was evaluated by a self-report scale for mobility, fatigue, bowel patterns, appetite, insomnia, incidence and severity of nausea, and weight changes. No reliability or validity information was reported for the Likert-type scale. Although Knobf found generally lower than expected ratings of physical distress, fatigue ($p \leq .01$) and insomnia (significance not reported) were the symptoms regarded as most distressful.

Psychologic distress was evaluated on a five-point self-report Likert-type scale; no reliability or validity support was reported. Items measured included diagnosis, loss of breast, survival.

financial burden, appearance, outlook, concentration, and mood. Knobf (1986) stated psychologic distress was reported to a greater degree than physical distress, as demonstrated by consistently higher scores.

Ehlke (1988) also studied breast cancer patients receiving chemotherapy in the outpatient setting. She sought to determine what variables were significantly related to symptom distress in a sample of 107. Symptom distress was measured using the Symptom Distress Scale (SDS); test-retest reliability was reported to be $r = .78$. Measurement of health locus of control was conducted using the Multidimensional Health Locus of Control Scale. Test-retest reliability for this instrument was .69 for the internal subscale, .75 for the powerful others subscale, and .69 for the chance subscale. Partial predictive validity for the instrument was supported by a positive correlation between high scores on the internal health locus of control subscale and good health status. Perception of social support was measured by the Norbeck Social Support Questionnaire. Test-retest reliabilities for this instrument were reported to range from $r = .85$ to .92. Internal consistency estimates ranged from $r = .89$ to .92.

Although Ehlke (1988) found minimal symptom distress in her sample, SDS scores were significantly related to perception of illness ($r = .23$; $p = .01$), internal health locus of control ($r = -.36$; $p < .001$), and chance health locus of control ($r = .21$; $p = .03$). Symptom distress was not significantly related to social support, powerful

others health locus of control, stage of disease, or aggressiveness of chemotherapy.

Holmes (1991) used a modified Symptom Distress Scale (Holmes, 1989) to investigate the incidence of symptom distress in two hospitalized cancer patient populations: those receiving chemotherapy ($n = 22$) and those undergoing radiotherapy ($n = 29$). Reported reliability of the instrument yielded a coefficient alpha of .94 in the chemotherapy patients and .91 in the radiotherapy group. Content validity was established through reference to previous literature (Schneider, 1978; McCorkle & Young, 1978), comparison to previous findings (Holmes, 1989; Holmes & Eburn, 1989), and consultation with expert clinical practitioners in cancer.

Results indicated that, although overall symptom distress was similar between chemotherapy and radiotherapy patients, considerable individual variation existed in the extent of that distress. In addition, the symptoms causing distress appeared to differ between groups. Tiredness was reported as the most common complaint. The chemotherapy patients also complained of an inability to concentrate, mood changes, and alterations in appearance. Radiotherapy patients most commonly reported significant distress due to pain, altered appearance, constipation, and appetite change. Holmes (1991) suggested that the modified Symptom Distress Scale may be a useful addition to the assessment of individual patients while also providing a means to evaluate the effects of interventions designed to alleviate physical distress.

Modified Symptom Distress Scale

The Symptom Distress Scale (SDS) (McCorkle & Young, 1978) was originally constructed during the course of two pilot studies. The purpose of the first study was to identify human concerns of patients receiving cancer treatments. During the second study, a symptom distress scale was developed to facilitate measuring the degree of distress perceived by the patient. The final scale consisted of 10 items: nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration and appearance.

To use the instrument, a single symptom on a scale from one to five was placed on a five-by-seven card. A score of one represented the least amount of distress for a given symptom and a score of five represented extreme distress; scores of two, three and four represented intermediate levels of distress. Ten cards representing the 10 symptoms were given to patients, one at a time and in the same order. Patients were asked to circle the number that most closely measured how they perceived their distress at that moment or for that day. Therefore, total symptom distress scores could range from a low of 10 to a high of 50 (McCorkle & Young, 1978).

The scale was originally tested on 53 patients with advanced medical conditions; the standardized alpha was 0.83. Of the 45 cancer patients in this group who completed all 10 items on the symptom distress scale, 28 (62.2%) indicated a high level of distress for at least one or more of the items. Thirteen (46%) of

these 28 cancer patients also indicated a high level of distress for at least three or more of the items. Face and content validity for the scale were supported since the symptoms had been identified as major concerns during the first pilot study (McCorkle & Young, 1978).

Holmes and Dickerson (1987) drew from the SDS (McCorkle & Young, 1978) in a comparative evaluation of visual analogue and Likert-type scales. Two groups of items were selected for measurement in a proposed self-assessment instrument. The first group was derived from the SDS and included aspects related to both the symptoms of disease and the side effects of treatment. The second group of items assessed the impact of such symptoms on activities of daily living. Dividing the items into two sections permitted calculation of the contribution of symptom distress to the total overall score. The resultant questionnaire was then adapted to three formats: a visual analogue scale (VAS), a five-point scale, and a six-point scale. The various scales for a particular item on the questionnaire were anchored by identical written statements representing the possible extremes of a subjective response.

Holmes and Dickerson (1987) proceeded to interview a convenience sample of 72 patients drawn from all those admitted to an oncology unit. Participants were asked to complete one form of the questionnaire on two occasions 60-90 minutes apart. The two Likert-type scales and the VAS were allocated on a random basis with the aim being to obtain 20 completed pairs for each type.

Reliability of the instrument was established using the test-retest method and by computation of Cronbach's coefficient alpha. The highest reliability coefficient was obtained using the VAS (0.97, $p < 0.001$); the six-point scale produced the lowest coefficient (0.72, $p > 0.001$). The coefficient of stability indicated all questions to be stable (Holmes & Dickerson, 1987).

Since analysis of variance showed no significant difference between the responses obtained using any of the scales, the authors concluded there was no statistical basis for selecting one scale in preference to another. They stated use of the VAS instrument was associated with fewer problems of completion; once explained to patients, it was reportedly simple and straightforward to use and permitted greater flexibility and discrimination between responses to individual items. It was also possible to measure a response with considerable accuracy and to distinguish between areas of greater and lesser concern. Holmes and Dickerson (1987) therefore decided that the responses obtained using the VAS instrument were more likely to reflect patients' true feelings.

Subsequently, Holmes (1989) constructed a symptom distress questionnaire based on a visual analogue scale. Stating the "flash-card" approach of McCorkle and Young's (1978) Symptom Distress Scale appeared clumsy and disturbing to the patient's concentration, she elected to use a continuous questionnaire to simplify administration. Additionally, she modified the instrument to an 11-item questionnaire by substituting the items "diarrhea" and

"constipation" for "bowel pattern." Each item was represented by a title and a 100 mm visual analogue scale anchored with descriptive phrases. The right end of the scale was represented as absence of a symptom and the left designated the opposite or extreme state.

The reliability of the modified scale ($\alpha = .97$) exceeded the reliability of the original ($\alpha = .82$) (McCorkle & Young, 1978). Content validity was evaluated by reference to previous literature (Hinton, 1963; McCorkle & Young, 1978; Schneider, 1978) and by seeking opinions from the patients included in the study. No significant omissions were identified by the latter. According to Holmes (1989), validity was supported by the high reliability coefficient and further enhanced by the results of the principle components analysis.

Initially, a pilot test with 30 patients was performed to evaluate issues related to administration of the instrument. After identifying the best method for giving instructions about the tool, Holmes (1989) conducted a study using a heterogeneous cross-sectional sample of 120 cancer patients admitted to a regional oncology unit. She found the scale straightforward, quick, and easy to use. The scale also appeared to be acceptable to patients since no one refused to participate or withdrew from the study once in possession of the questionnaire.

Of the 120 patients included in the study, 73% indicated significant distress from at least one symptom, 55% from two or more, and 28% from at least five symptoms. Only 25% had evidence

of widespread or advanced disease, suggesting that the incidence of symptom distress was not necessarily dependent on the extent of disease. Holmes (1989) also found that, with the exception of diarrhea, all symptoms together accounted for 46.4% of the variance in total scores, suggesting equal contribution of these symptoms to the total score obtained. Diarrhea alone was the second component carrying a highly significant loading and accounted for 9.9% of the variance.

In 1989, Holmes and Eburn used the modified Symptom Distress Scale (mSDS) to compare patients' and nurses' perceptions of symptom distress in cancer. A heterogeneous sample of cancer patients ($n = 53$) and nurses caring for those patients ($n = 53$) simultaneously completed a modified version of the McCorkle and Young (1978) Symptom Distress Scale. Reliability for the instrument in this study yielded a coefficient alpha of .97 for the patient group and .81 for the nurse group.

Nurses were asked to rate their patients according to how they perceived the patients were feeling with regard to each particular symptom. When the scores were compared for congruency, findings suggested that although nurses were apparently able to estimate the degree of distress related to changes in mobility and appearance or the presence of diarrhea, constipation and tiredness, they were less effective in perceiving the degree of distress due to less visible symptoms such as pain, nausea, anorexia, sleeping disturbances, concentration, and mood. Also noted was a trend for nurses to

overestimate the degree of distress when this was compared with the patients' self-assessment. Holmes and Eburn (1989) concluded that results of their study supported the need for patient self-assessment since less visible symptoms were less accurately perceived by nurses.

However, accurate nursing assessment is the foundation for sound nursing care and may be instrumental in early diagnosis of complications of both cancer and its treatment. Replication of the Holmes and Eburn (1989) study was performed to further explore the nature of nurses' and patients' perceptions of symptom distress in cancer.

Summary

King's Open Systems Framework provided the foundation for conceptualization of this study. Cancer is viewed as a disturbance in the patient's life cycle requiring continual adaptation to stresses precipitated by the disease process and its treatment. Patients and nurses establish relationships in nursing situations to cope with this chronic illness and to adjust to any necessary changes in activities of daily living. Perception is fundamental to this interaction process but is also acknowledged to be a highly subjective experience. Variations in perception between patients and nurses have been described in the literature. Many symptoms resulting from cancer treatment as well as the degree of symptom distress are phenomena perceived only by the patient and not

directly observable by others. Numerous investigators have studied the occurrence of symptoms and symptom distress and have used various measures to evaluate it. The evolution of one instrument of particular interest to this study, the modified Symptom Distress Scale, was described as relevant for further examination of nurses' and cancer patients perceptions of symptom distress.

CHAPTER THREE

Methodology

The research design, setting and sample criteria, protection of human subjects, and instruments are described in this chapter. Also addressed are the data collection procedure and data analysis plan.

Research Design

This study used a comparative descriptive design to replicate the work of Holmes and Eburn (1989). Accordingly, perceptions of symptom distress were examined in a heterogeneous group of hospitalized cancer patients and their assigned registered nurse caregivers. A comparative descriptive design examines and describes differences in variables in two or more groups occurring naturally in a setting (Burns & Grove, 1987). The variable was perception of symptom distress; the compared groups were cancer patients and the nurses caring for them.

Setting and Sample

The target patient population was adults admitted to the hospital with cancer. A convenience sample of 32 paired subjects, consisting of hospitalized oncology patients and their assigned nurses, was obtained from four hospitals in a large southwestern city. The settings included an inpatient medical/oncology unit in a tertiary care center, an inpatient oncology unit in a regional medical

center, three inpatient medical units in a regional veterans hospital, and an inpatient medical unit in a community hospital.

To be included in the study, patients met the following criteria:

- 1) Male or female, 18 years of age or older to qualify as an adult;
- 2) Able to speak, read, and write the English language; and
- 3) Currently hospitalized for medical treatment related to a cancer diagnosis.

Patients were excluded if they were in the diagnostic phase of care or had just been informed of a cancer diagnosis during the current admission.

The criteria for participation of the nurses in the study included:

- 1) Currently licensed registered nurse;
- 2) Permanent assignment for a minimum of three months to the unit where the patient was hospitalized;
- 3) Assignment as the primary nurse to the selected patient for at least four hours prior to participation in the study; and
- 4) Verbalized willingness to complete a questionnaire within one hour of the patient's completion of a questionnaire.

Protection of Human Subjects

Written permission to conduct this study was obtained from the University of Arizona Human Subjects Committee (Appendix A)

and each hospital used for data collection. Only those subjects who voluntarily agreed to participate in the study were included. A verbal explanation of the purpose of the study and its risks and benefits was given to each participant. A written explanation was included on the consent form for patients (Appendix B) and the disclaimer for nurses (Appendix C).

There were no known risks. All subjects were informed that participation in the study was voluntary. Patients were informed that a decision to participate or withdraw would in no way affect the medical or nursing care they received. Nurses were informed that a decision to participate or withdraw would not affect their employment. The only cost to subjects was the time needed to complete one paper and pencil questionnaire.

A code number for each patient and nurse was written on the questionnaire and demographic forms. Neither patients' nor nurses' names appeared on any of the data collection forms. Patients and nurses were instructed not to write their name on the forms to further protect their anonymity.

Instruments

Patient Demographic Data Form (PDDF)

The Patient Demographic Data Form (Appendix D) was developed based on a review of the literature. Information pertaining to age, sex, employment status, and ethnicity provided basic information. Disease-related information included primary

diagnosis, date of diagnosis, stage of disease, and type of cancer-related treatments received since diagnosis. In addition, the length of the current hospitalization as well as number of previous hospitalizations were ascertained.

Nurse Demographic Data Form (NDDF)

The Nurse Demographic Data Form (Appendix E) was used to collect information from the nurses concerning age, sex, ethnicity, employment status (full-time, part-time), highest degree/diploma currently held, and the number of years of professional nursing experience. Information was also ascertained concerning experience in cancer nursing and certification in oncology nursing.

Modified Symptom Distress Scale (mSDS)

The choice of instrument for this study was influenced by the replicative nature of the research. Accordingly, a revised version of the questionnaire used by Holmes and Eburn (1989) was selected and permission to use it was obtained from the publisher (Appendix F). The modified Symptom Distress Scale (Holmes, 1991) was a 13-item questionnaire used to measure perceptions of symptom distress (Appendix G). It consisted of 11 items in the form of a visual analogue scale (VAS), followed by two open-ended questions. The questions asked which symptom, if any, caused severe distress and whether symptoms were believed to be caused by the disease or the treatment.

As a technique for measuring subjective phenomena, the VAS has become increasingly evident in nursing research (Wewers & Lowe, 1990). Freyd (1923) referred to it as a Graphic Rating Scale and enumerated its various advantages: simple and easily grasped; interesting and requiring little rater motivation; quickly filled out while enabling the rater to make fine discriminations without the constraints of quantitative terms; use of descriptive terminology to aid in rating a trait; and simply and easily scored with many options for fineness of scoring. Lee and Kieckhefer (1989) also noted that it does not require a high level of reading ability.

Several studies (Holmes, 1989; Holmes & Dickerson, 1987; Holmes & Eburn, 1989; Holmes, 1991) supported the reliability and validity of the mSDS. Additionally, when the Symptom Distress Scale in visual analogue form was compared to five- and six-point Likert-type forms, the VAS was shown to be the method of choice due to its flexibility and capacity to distinguish variations in responses to individual items (Holmes & Dickerson, 1987). It was also possible to measure responses with considerable accuracy and to distinguish between areas of greater and lesser concern. On this basis, Holmes and Dickerson decided that the responses using the VAS, or modified Symptom Distress Scale, were more likely to accurately reflect the patient's true feelings.

Data Collection Procedure

The investigator approached inpatient nurses assigned to care for one or more cancer patients. If the nurses verbalized willingness to complete a questionnaire within the same hour as their patients completed one, the investigator approached potential patient participants. The investigator explained the study to each member of the subject pairs with respect to purpose, method, risks/benefits, and time involved (approximately 10 to 15 minutes). Once a time frame agreeable to both patient and nurse was established for completion of the instrument, the participants were each given a questionnaire and disclaimer form (nurse) or consent form (patient). Once in possession of the questionnaire, they were asked to refrain from discussing symptoms on the instrument until after it was returned to the investigator. Both patients and nurses were asked to complete the questionnaire within one hour after receiving it from the investigator.

In addition to brief written instructions attached to the questionnaire, detailed directions for completing the questionnaire were explained by the investigator using a standardized format and a sample item typed on a four by six inch card. Various marks across this sample visual analogue scale were explained as examples of where individuals with varying degrees of perceived distress might indicate their responses. After verbalizing understanding of the procedure, participants were then referred to the questionnaire and asked to place a mark across the line of each item at that point

which they thought best described the amount of perceived distress from a symptom. Nurses were asked to rate their patients according to how they perceived the patients were feeling with regard to each particular symptom. The investigator not only was available to clarify or answer any questions regarding the questionnaire, but also offered to stay in the room with the patient during instrument completion if desired.

After the patient consented to participate in the study, the investigator obtained patient demographic data by chart review. Nurse demographic data were obtained from a demographic data sheet attached to the questionnaire. No more than one questionnaire was completed by a nurse or patient.

Data Analysis Plan

Responses were scored by assigning a value of 100 to the end of the line indicating absence of symptom distress and a value of zero to the opposite end. Distance along the line was then measured in millimeters from zero so that higher scores indicated less severe symptom distress. Thus, the visual analogue scale was assigned numerical value and provided a means to compare individuals.

Descriptive statistics, including frequency distributions, ranges, means, and standard deviations, were used to describe demographic data. Responses to the two general questions concerning symptoms were summarized. Internal consistency

reliability of the instrument for both the nurse and the patient groups was analyzed using Cronbach's alpha.

Research question one, addressing self-assessment of perceived symptom distress in hospitalized patients with cancer, and research question two, addressing the assessment of symptom distress as perceived by nurses caring for those patients, were analyzed using descriptive statistics for each item of the instrument. Research question three, comparing nurses' assessments of symptom distress with their patients' self-assessments, was analyzed by means of Student's t-test for paired data. The two-tailed level of probability for this study was established at $p \leq .05$.

Summary

A comparative descriptive design was used to investigate perceptions of symptom distress as reported by hospitalized cancer patients and as perceived by the nurses caring for them. The modified Symptom Distress Scale had proven psychometric properties in these populations and was selected for data collection. Data analysis included descriptive statistics and paired t-tests to compare patients' and nurses' perceptions.

CHAPTER FOUR

Results of Data Analysis

This chapter describes the characteristics of both the patient and the nurse samples and reports on the reliability of the instrument with each group. Statistical analysis of the research questions is presented in conjunction with a report of the major findings.

Description of the Samples

Demographic Characteristics of Patients

A total of 37 patients was approached for participation in the study. Three patients declined to participate. One stated she did not want to get involved and one reported feeling too ill to participate. The third patient withdrew during the process of obtaining informed consent, stating it was not a good time and he did not "want to deal with it." Questionnaires returned from two other patients were unusable.

Thus, a convenience sample of 16 (50%) women and 16 men (50%) comprised the patient population for this study. Ages ranged from 18 years to 81 years ($M = 58.1$, $SD = 16.54$). The majority of patients ($n = 28$, 87.5%) were Caucasian. The remainder were Hispanic ($n = 2$, 6.3%), Indian ($n = 1$, 3.1%), or Oriental ($n = 1$, 3.1%). Nineteen patients (59.4%) were retired, eight (25%) were unemployed, and five (15.6%) were currently employed full-time.

Primary diagnosis and time since initial diagnosis were noted to ascertain disease-related information. Diagnoses were grouped into eight categories and are described in Table 1. The most common malignancies were leukemia (21.9%), lymphoma (18.8%), and lung cancer (15.6%). Time since initial diagnosis is categorized in Table 2 and ranged from less than one month to 26 years (\bar{M} = 40.4 months, \bar{SD} = 71.2 months). An interesting observation for this group is that the median time since diagnosis was 12 months.

Besides the primary cancer diagnosis, other illnesses documented in the medical record were noted for each patient. These illnesses were categorized into 11 groups and frequencies are displayed in Table 3. Many patients had multiple illnesses; 13 patients (40.6%) had some form of cardiovascular illness documented.

Treatment-related information included past and present cancer therapies and is presented in Table 4. Almost half of the sample (n = 15, 46.9%) was not receiving any cancer therapy at the time of the survey. However, of the remainder, 88% (n = 15) were currently receiving chemotherapy. Additionally, chemotherapy was the predominant therapeutic modality noted in treatment history; the majority of patients (n = 26, 81.3%) had received at least one antineoplastic agent in the past.

Reasons for hospitalization varied widely but were grouped into three categories: treatment (chemotherapy), treatment side effects, and disease symptomatology. Fifteen patients (46.9%) were

Table 1

Primary Diagnoses in Patient Sample (n = 32)

Diagnosis	Frequency	Percentage
Leukemia	7	21.9
Lymphomas	6	18.8
Lung	5	15.6
Ovarian, breast	4	12.5
Alimentary tract	3	9.4
Urologic, male genital	3	9.4
Head and neck	2	6.2
Soft tissue	2	6.2
Total	32	100.0

Table 2

Time Since Initial Diagnosis: Patient Sample (n = 32)

Time interval	Frequency	Percentage
1 to 6 months	13	40.6
6 to 12 months	3	9.4
1 to 2 years	7	21.9
2 to 5 years	3	9.4
More than 5 years	6	18.7
Total	32	100.0

Table 3

Other Illnesses in Patient Sample (n = 32)

Illness	Frequency	Percentage
Cardiovascular	13	40.6
Metabolic/endocrine	10	31.3
Respiratory	7	21.9
Neurologic	6	18.8
Urologic/reproductive	6	18.8
Digestive	5	15.6
None	4	12.5
Eye	2	6.2
Infectious/viral	2	6.2
Musculoskeletal	2	6.2
Psychiatric	2	6.2
Skin	2	6.2

Note. Frequencies do not total 32; many patients had more than one other documented illness.

Table 4

Past and Present Patient Treatment Information (n = 32)

Modality	Previous recipient	Percentage	Current recipient	Percentage
None	2	6.3	15	46.9
Chemotherapy	26	81.2	15	46.9
Surgery	9	28.1		
Radiotherapy	9	28.1		
Biotherapy	4	12.5	2	6.3
Bone marrow transplant	1	3.1	1	3.1
Hyperthermia	1	3.1		

Note. Frequencies do not total 32; some patients received multiple therapies.

admitted specifically to receive chemotherapy. One of these patients also received a bone marrow rescue. Nine patients (28.1%) were admitted for management of treatment side effects. These included rule-out sepsis, mucositis, anemia, neutropenia, radiation esophagitis, nausea/vomiting, and dehydration. Eight (25%) patients were admitted for disease complications and/or palliation. These included pleural and pericardial effusions, pneumonia, intractable back pain, thrombophlebitis, and nursing home placement.

The number of days patients had been hospitalized during the current admission ranged from less than one day to 24 days ($M = 4.9$, $SD = 6.6$, median = 2). The number of previous hospitalizations ranged from none to "too numerous to count." Out of 31 patients, slightly more than half ($n = 17$, 54.8%) had seven or more previous admissions, although not all were related specifically to cancer.

Demographic Characteristics of Nurses

Each of the nurses was currently assigned to only one of the subjects in the patient sample. As a group, the nurses ranged in age from 25 years to 62 years ($M = 36.3$, $SD = 9.14$) and the majority were female ($n = 29$, 90.6%). Of the nurses who responded to the question concerning ethnicity, 29 (90.6%) were Caucasian. One nurse was Black ($n = 1$, 3.1%); the remainder ($n = 2$, 6.2%) did not specify an ethnic group.

Job related information is displayed in Table 5. The majority of nurses ($n = 27$, 84.4%) were employed full-time. Twenty-eight of the responding nurses (90.3%) were working as general staff nurses.

The highest education achieved by over half of the nurses ($n = 17$, 53.1%) was a diploma or associate degree in nursing. Fifteen of the nurses (40.6%) had a baccalaureate in nursing. Of this latter group, two also had a Bachelor of Arts degree.

Years of nursing experience ranged from less than one year to 32 years ($M = 8.2$, $SD = 9.15$, median = 5.5). The number of years in cancer nursing ranged from none to 15 ($M = 4.7$, $SD = 4.6$, median = 2) and the majority of nurses ($n = 23$, 71.9%) were not certified in oncology nursing. Finally, the number of days the nurse had been assigned to the patient ranged from one to 14 ($M = 2.5$, $SD = 3.21$); especially noteworthy is that the median was one.

Instrument Reliability

Internal consistency reliability of the Modified Symptom Distress Scale was estimated for both the patient and the nurse groups using Cronbach's coefficient alpha. The criterion for adequate reliability was established at .70. The reliability coefficient of .83 for the patients was somewhat low compared with Holmes' (1989) finding of .97 for her patient group. However, a coefficient alpha of .79 for the nurses was consistent with Holmes' finding of .81 for her nurse group.

Table 5

Nurse Job Information (n = 32)

Job title	Full-time	Part-time
Staff nurse	24	5
Bone marrow transplant staff nurse	1	
Clinical nurse leader	1	
Assistant nurse manager	1	
Total	27	5

Statistical Analysis of the Research Questions

Using a VAS format, the Modified Symptom Distress Scale (mSDS) (Holmes, 1991) required a mark placed on a horizontal 100 mm line for each of 11 items. The response for each item could be scored from 0 to 100; higher scores indicated less distress. A total score of 1100 was possible for the scale.

Research Question 1. What are the self-assessments of symptom distress as perceived by hospitalized patients with cancer?

Descriptive statistics were used to analyze perceptions of symptom distress within the patient group. Table 6 illustrates the range, means, and standard deviations for each of the items and for the total scale. While Holmes and Eburn (1989) reported a mean of 824.3 ± 157.7 for the total symptom distress score, the mean for this sample was 718.5, with a standard deviation of 181.4. The large standard deviations on individual items were indications of considerable variability within this group.

Over half the patient sample rated both tiredness ($n = 19$, 59.4%) and appearance ($n = 16$, 51.6%) at less than 50 mm on the scale, indicating higher levels of distress. Of these, tiredness and appearance were rated at less than 25 mm by 36.8% and 50%, respectively. Sleep ($n = 15$, 46.9%) was the next most frequent source of distress rated at less than 50 mm, followed by appetite ($n = 13$, 40.6%) and mood ($n = 11$, 34.4%). While constipation was rated

Table 6

Modified Symptom Distress Scale Item Means and Standard
Deviations--Patient Scores

Symptom	N	Range	Mean	SD
Pain	32	19--100	76.5	23.5
Nausea	32	13--100	80.81	24.4
Appetite	32	4--100	59.56	29.81
Sleep	32	1--100	58.03	30.02
Mobility	32	1--98	58.16	26.82
Diarrhea	31	48--100	87.32	16.77
Constipation	32	2--100	66.78	32.70
Tired	32	6--100	47.44	26.43
Concentration	32	16--100	70.06	25.57
Mood	32	10--99	64.41	27.21
Appearance	31	0--100	53.84	32.37
Total Scale		295--1048	718.5	181.14

by 10 patients (31.3%) at less than 50 mm, half of these ratings were at less than 25 mm. On the other hand, diarrhea was rated by only one patient at less than 50 mm. Only five patients (15.6%) rated pain at less than 50 mm and of these five, only one rated it at less than 25 mm.

Research Question 2. What is the assessment of symptom distress as perceived by nurses caring for those hospitalized patients?

Descriptive statistics were used to analyze nurses' perceptions of patients' symptom distress and findings are illustrated in Table 7. In their study, Holmes and Eburn (1989) reported a mean of 714.4 ± 171.3 for the total symptom distress score; the findings for this sample ($M = 678.1$, $SD = 185.8$) were very similar. As with the patient sample, large standard deviations on individual items were indications of considerable variability among the nurses' responses.

Over half the nurse sample ($n = 19$, 61.3%) rated both tiredness and mood at less than 50 mm on the scale, indicating higher levels of distress. Appearance ($n = 15$, 48.4%) was the next most frequent source of distress rated at less than 50 mm, followed by appetite ($n = 13$, 40.6%) and pain ($n = 12$, 37.5%).

Table 7

Modified Symptom Distress Scale Item Means and Standard
Deviations--Nurse Scores

Symptom	N	Range	Mean	SD
Pain	32	16--100	63.78	27.35
Nausea	32	20--100	74.22	25.85
Appetite	32	0--100	58.12	31.39
Sleep	32	14--100	59.81	24.61
Mobility	32	32--100	68.59	23.37
Diarrhea	30	23--100	88.33	20.62
Constipation	29	1--100	73.41	32.46
Tired	31	6--92	45.23	20.55
Concentration	31	20--100	66.52	25.62
Mood	31	12--100	46.61	22.0
Appearance	31	3--100	52.48	29.5
Total Scale		255--1039	678.5	185.75

Research Question 3. How do assessments of symptom distress as perceived by hospitalized cancer patients compare with assessments of symptom distress as perceived by their nurses?

Since this was a replication study, Student's t-test for paired data was performed for purposes of comparison. The findings are presented in Table 8. Statistically significant differences in perception were noted for pain ($t[31] = 2.82, p < .05$) and mood ($t[30] = 3.99, p < .001$). These findings are only partially comparable to those of Holmes (1989) who noted statistically significant differences not only for the symptoms of pain ($t = 2.30, p > .05$) and mood ($t = 4.97, p > .001$), but also for nausea ($t = 5.02, p > .001$), appetite ($t = 4.47, p > .001$), sleep ($t = 2.34, p > .05$), and concentration ($t = 2.31, p > .05$).

Because the mSDS contained a large number of variables, Hotelling's T^2 was performed as an additional, more conservative measure of the differences between the patients' and nurses' perceptions of symptom distress. Bonferroni's procedure was used to establish a significance level of .001. As may be seen in Table 9, only the difference in mood scores was found to be statistically significant ($F[1,25] = 21.75, p < .001$).

Hotelling's T^2 was also performed with the effect of patient gender factored in. However, no statistically significant differences were found with this analysis.

Table 8

Patient and Nurse Difference Scores on Modified Symptom Distress Scale--Paired t-tests

Symptom	n	Mean raw patient score	Mean raw nurse score	t	p
Pain	32	76.5	63.78	2.82	.008*
Nausea	32	80.81	74.22	1.27	.213
Appetite	32	59.56	58.12	.28	.778
Sleep	32	58.03	59.81	-.31	.760
Mobility	32	58.16	68.59	-1.63	.114
Diarrhea	29	87.97	87.93	.01	.993
Constipation	29	68.86	73.41	-.87	.393
Tired	31	47.55	45.23	.39	.702
Concentration	31	70.87	66.52	.64	.527
Mood	31	64.74	46.61	3.99	.000**
Appearance	30	55.1	53.13	.24	.810

*p < .05

**p < .001

Table 9

Patient and Nurse Difference Scores on Modified Symptom Distress Scale--Hotelling's T^2

Symptom	E	Sig of E
Pain	7.5	.011
Nausea	3.09	.091
Appetite	.33	.573
Sleep	.06	.803
Mobility	1.09	.307
Diarrhea	.00	1.00
Constipation	2.17	.153
Tired	.29	.594
Concentration	.99	.328
Mood	21.75	.000*
Appearance	.3	.590

* $p < .001$

Additional Findings

Pearson correlation coefficients were calculated for 27 complete cases to measure the relationship between the number of days hospitalized and the differences in the patients' and nurses' scores for each symptom. No statistically significant relationship was identified.

Using the pooled t-test, differences in the patients' and nurses' scores for each of the symptom variables was compared to level of nursing education, certification in oncology nursing, and number of days the nurse had been caring for the patient. The number of days was categorized into two groups, the first consisting of one day or less and the second consisting of two or more days.

No statistically significant difference was found between scores and level of education. However, when compared with oncology nursing certification, the difference in scores between nurses and patients on the symptom of sleep approached statistical significance ($t[30] = 1.93, p < .07$). Also approaching statistical significance was the difference between nurses and patients on the symptom of appearance when compared with the number of days nurses had cared for their patients. This comparison yielded a $t(31) = 2.01, p < .06$.

Multiple regression analysis was used to examine the relationships between several independent variables (patient age, nurse age, number of previous hospitalizations, number of years in nursing,

number of years in cancer nursing) and the dependent variables of difference scores for each of the symptoms. For three symptoms, either number of years in nursing or number of years in cancer nursing contributed to a statistically significant amount of variance.

The R^2 for number of years in cancer nursing was 18.3% and significant at $<.03$ for differences in sleep scores (Table 10). The R^2 for number of years in nursing was 17.6% and significant at $<.03$ for differences in mobility scores (Table 11). The R^2 for number of years in cancer nursing was 20.6% and significant at $<.02$ for differences in appearance scores (Table 12). Additionally, the negative b -weights for all of these variables indicated a negative correlation. In other words, as the number of years in nursing or cancer nursing increased, the differences between nurses' and patients' scores decreased.

Responses to two open-ended questions at the conclusion of the mSDS were summarized. Answers varied widely among the 22 pairs who answered the question about whether any one symptom was causing severe distress. Nine nurse-patient pairs agreed on which symptom was causing the most distress. Among the answers were hair loss, constipation, nausea/vomiting, sore throat, shortness of breath, epigastric discomfort, and pain.

The other question asked whether the subject thought the symptoms experienced were caused by the disease or the treatment.

Table 10

Stepwise Multiple Regression Analysis--Selected Independent
Variables With Difference in Sleep Scores (n = 32)

Step	Variable	b wt	SE	Beta	t	Sig of T
1	Years in cancer nursing	-3.33	1.4	-.43	-2.37	.026

Table 11

Stepwise Multiple Regression Analysis--Selected Independent Variables With Difference in Mobility Scores (n = 32)

Step	Variable	b wt	SE	Beta	t	Sig of T
1	Years in nursing	-1.76	.76	-.42	-2.32	.029

Table 12

Stepwise Multiple Regression Analysis--Selected Independent
Variables With Difference in Appearance Scores (n = 31)

Step	Variable	b wt	SE	Beta	t	Sig of T
1	Years in cancer nursing	-4.33	1.7	-.454	-2.55	.017

Of the 25 nurse-patient pairs who responded, 12 pairs agreed on the source of symptoms. Of these 12, five pairs stated it was the treatment, three stated it was the disease, and four responded that both the disease and the treatment contributed to the symptoms. Five nurse-patient pairs disagreed as to the cause of symptoms.

Summary

A convenience sample of 32 oncology patients were paired for data analysis with the nurses assigned to care for them. The demographic characteristics of each group were described. Acceptable internal consistency reliability of the Modified Symptom Distress Scale was established for both groups. Patients' perceptions of symptom distress and nurses' perceptions of their patients' symptom distress were analyzed using descriptive statistics. Statistically significant differences were noted between patients' and nurses' perceptions of pain and mood when the Student's t-test for paired data was performed. However, Hotelling's T^2 revealed a statistically significant difference only in mood.

CHAPTER FIVE

Discussion, Conclusions, and Recommendations

Major findings are interpreted in this chapter and subsequent conclusions are presented. Following a statement of the study's limitations, nursing practice implications and recommendations for further research are proposed.

Discussion of the Findings

To interpret the findings in this study, a basis of comparison was established using the work of other investigators (Holmes, 1989; Holmes & Eburn, 1989; McCorkle & Young, 1978). When McCorkle & Young (1978) tested the original Symptom Distress Scale (SDS), a level of distress was assigned to each item's score on the scale. Accordingly, scores of one or two depicted low levels of distress, a score of three described moderate distress, and scores of four or five indicated high distress levels.

Holmes (1989) noted that each score on the SDS could be represented as a 25% increment on the modified Symptom Distress Scale (mSDS). Thus, while a score of five on the SDS was equivalent to 0 mm on the mSDS, a score of four corresponded to 25 mm, a score of three to 50 mm, a score of two to 75 mm, and a score of one to 100 mm. Although Holmes (1989, 1991) acknowledged that one cannot assume that the interval between points on the SDS is equal, she noted that giving numerical values to visual scales provides the

method through which samples can be compared. Accordingly, she elected to consider 25 mm on the mSDS to be equivalent to four on the SDS and thus the upper limit to determine high levels of distress. Her interpretation was supported during the present study: several patients indicated that the midpoint of the mSDS items represented to them a moderate or 50% level of distress.

Based on these comparisons, the mean score for the total scale in this study indicated patients were experiencing a low to moderate level of symptom distress. Tiredness, appearance, sleep, and appetite were the four symptoms patients most frequently indicated as significant sources of symptom distress. In this sample, pain was not generally considered a significant source of symptom distress.

Similarly, Holmes and Eburn (1989), whose work this study replicates, also found that tiredness, appearance, and sleep were among the top four symptoms scored at less than 50 mm. Although patients in their study reported mood as the third most frequent source of symptom distress, 30.2% ($n = 16$) were affected, similar to the 34.4% ($n = 11$) affected in this study. Diarrhea was indicated as the least significant cause of distress in both studies.

In two previous studies (Holmes, 1989; McCorkle & Young, 1978), reported findings were mixed when compared with those of the present study. Changes in bowel pattern were reported to be the most frequent source of high level symptom distress (rated 4 on the SDS or ≤ 25 mm on the mSDS), in contrast to present study findings.

However, in findings similar to this study, the previous investigators also reported that appearance was the second most frequent source of significant symptom distress. Furthermore, Holmes (1989) found that tiredness ranked as the third most frequent source of significant symptom distress.

Nurses' perceptions of symptom distress were similar to the patients; tiredness, appearance, and appetite were among the four most frequent sources of symptom distress rated at less than 50 mm. However, consistent with Holmes and Eburn's (1989) report, the most significant finding in this study was that nurses generally rated mood as the most frequent contributor to higher levels of symptom distress. Although this contrasted markedly with the patients' self-assessments, mood tends to be a very subjective symptom and it is generally not surprising that a difference was noted.

Jennings and Muhlenkamp (1981) noted a similar phenomenon in a study of cancer patients and their caregivers; for each affective state measured, caregivers rated patients as feeling considerably worse than the patients themselves reported feeling. The authors discussed their findings in relation to Wright's (1960) requirement of mourning hypothesis, a conceptualization used to explain differences in perception between disabled individuals' perceptions of themselves and others' perceptions of them. Wright stated that when people feel a need to safeguard their values, they may insist that disabled or otherwise "unfortunate" people are suffering, even

when they appear not to be suffering. Similarly, Jennings and Muhlenkamp proposed that caregivers need to see patients as feeling negatively in order to reassure themselves that their value systems emphasizing health are intact.

The conceptual framework for this study (Figure 1) depicts the interaction between nurses and patients as a reciprocal process, with a continual giving and receiving of information and feedback (King, 1986). Nurses' overestimates of oncology patients' psychological pain will almost certainly be reflected in their interaction with the patients, perhaps as an expression of overconcern or protective communication. The misunderstanding of patients' affective states may result in feelings of isolation and loss of identity on the part of the patient. Additionally, the attribution of more negative feelings to patients than they actually experience might result in the patient attempting to reassure and support the nurse, by communicating in effect, "Don't worry about me" (Jennings & Muhlenkamp, 1981).

In other findings, nurses generally perceived patients as experiencing higher levels of distress from pain than indicated by the patients. This difference was statistically significant at $p < .05$ although statistical significance disappeared with additional more rigorous testing.

Differences in sleep scores between nurses and patients appeared to be a function of oncology nursing experience and possibly a reflection of oncology nursing certification. Differences

in appearance scores were also significantly correlated with the number of years in oncology nursing. Negative correlations in both of these relationships indicated that as the number of years in cancer nursing increased, the difference between patients' and nurses' scores decreased. Thus, the more cancer nursing experience nurses had, the more accurately they perceived patients' self-assessments of sleep and appearance.

Similarly, as the number of years in nursing increased, the differences in mobility scores between nurses and patients decreased. Thus, the more years of nursing experience nurses had, the more accurately they perceived patients' self-assessments of mobility.

Limitations of the Study

A major limitation to this study was the instrument used. Although most patients reported little or no difficulty completing the instrument, several patients exhibited some initial confusion when starting to respond to the questions. The general tendency in these patients was to write a comment above the line for the item or to circle one of the line's two anchors. Thus, as the researcher became more aware of difficulties encountered by patients in starting the questionnaire, instructions for instrument completion given to patients and nurses admitted later in the study may have been affected.

Patients also reported difficulty responding to some questions because of the descriptors on either end of the line. For example, regarding appetite, one patient stated his appetite was good--he wanted to eat--but he was unable to swallow because of pain. Once the pain was precipitated, he stated he did not want to face food. This is a slightly different interpretation than being unable to face food, which is the negative anchor for this item.

The question concerning appearance elicited some interesting comments. One patient who chose not to respond to the question stated that although her appearance had changed--she had lost 40 pounds--she considered that an improvement. Another patient responded to the question with the maximum negative rating and related her answer to her marked alopecia. However, she denied that it caused her severe distress. She recognized that it was a consequence of her treatment and was reversible.

Another patient stated that the negative descriptor for mood, "Could not feel more miserable," could refer to either physical or emotional manifestations. Multidimensional aspects of this and other constructs on the instrument may have complicated the measurement issue and made it impossible to identify which dimension was being evaluated by a subject (Wewers & Lowe, 1990).

Another limitation of the instrument is the lack of experiential grounding for the maximal descriptor. According to Wewers and Lowe (1990),

'No pain' is easily understood by subjects, whereas 'pain as bad as it can be' has no absolute value and could be argued to be unmeasurable. Therefore, any mark along the line between these two extremes is totally dependent upon the subject's unique interpretation of the maximal value and based on the subject's experience to date (pp. 233-234).

Study limitations also included the small sample size of 32. This was related to the criteria specifying participation of registered nurses only and to the data collection protocol which limited each nurse to completing only one questionnaire. The effects of the small sample size were compounded by the fact that occasionally either patients or nurses did not rate some items on the questionnaire, thus further limiting the comparisons possible.

The nonrandom nature of patient selection limits the generalizability of the findings. Although a heterogeneous sample was sought, convenience sampling resulted in almost half of the patients having hematologic malignancies. The sample was also drawn primarily from a population referred by nursing staff members. Patients judged to be too ill or at an emotionally vulnerable stage in their illness were thus screened from participation.

Nursing Implications

With such a small sample and the fairly circumscribed area of investigation, nursing implications may be somewhat limited. It is worth considering that nurses' assessments of patients' moods and pain may be influenced by assumptions related to the cancer

diagnosis and not by those patients' experiences. To facilitate communication that is more open and pertinent to the patient, it may behoove nurses to become more aware of personal attitudes.

Findings in this study lend support to the notion that cancer nursing experience improves nursing assessment of some symptoms. Presumably, this impacts on the nurse-patient interaction as well as the patient's cancer experience. Therefore, "it is incumbent on nurses who care for individuals with cancer to become knowledgeable about current cancer care practices so that they can provide optimal nursing care to these patients and families" (Longman, 1990, p. 1260).

Recommendations for Further Research

1. Replication of the study with a larger sample size to include outpatients as well as inpatients.
2. Investigation into how similarities or differences in patients' and nurses' perceptions of symptom distress affect the patient's cancer experience.
3. Exploration into how nurses' assessments of cancer patients' moods affect nurse-patient interactions.
4. Testing of the mSDS with other norm-referenced measures to more thoroughly evaluate validity of the scale.
5. Qualitative evaluation of various components of the mSDS.

Summary

Nurses' and patients' perceptions of symptom distress were generally congruent. Both groups identified tiredness, appearance, and appetite as significant sources of distress. However, a major difference between the two groups was found concerning mood. Nurses generally perceived mood as the most frequent contributor to higher levels of symptom distress, in marked contrast to patients' self-assessments. The two groups also differed in their perceptions of pain, although to a lesser degree than with mood.

While somewhat limited in scope, this study suggests that nurses' assessments of patients' moods and pain may be influenced by assumptions related to the cancer diagnosis. In order to positively impact on nurse-patient interactions, increased awareness of personal attitudes and an emphasis on cancer nursing education is encouraged.

APPENDIX A

HUMAN SUBJECTS APPROVAL

Human Subject Committee

THE UNIVERSITY OF
ARIZONA
HEALTH SCIENCES CENTER

James Warren Bldg 826B
Tucson, Arizona 85724
602/626-6721 or 626-7555

May 2, 1991

Rhonda L. Davis, BSN
College of Nursing
Arizona Health Sciences Center

**RE: PATIENTS' AND NURSES' PERCEPTION OF SYMPTOM DISTRESS IN CANCER-
A REPLICATION STUDY**

Dear Ms. Davis:

We received your above referenced project. Regulations published by the U.S. Department of Health and Human Services [45 CFR Part 46.101(b)(3)] exempt this type of research from review by our Committee.

Consult your department chairman for approval, the requirement of a subjects' consent form and any other departmental guidelines.

Thank you for informing us of your work. If you have any questions concerning the above, please contact this office.

Sincerely yours
William F. Denny

William F. Denny, M.D.
Chairman,
Human Subjects Committee

WFD:sj

cc: Departmental/College Review Committee

APPENDIX B

PATIENT CONSENT FORM

SUBJECT' S CONSENT

TITLE: Nurses' and Cancer Patients' Perceptions of Symptom Distress--A Replication Study

I AM BEING ASKED TO READ THE FOLLOWING MATERIAL TO ENSURE THAT I AM INFORMED OF THE NATURE OF THIS RESEARCH STUDY AND OF HOW I WILL PARTICIPATE IN IT, IF I CONSENT TO DO SO. SIGNING THIS FORM WILL INDICATE THAT I HAVE BEEN SO INFORMED AND THAT I GIVE MY CONSENT. FEDERAL REGULATIONS REQUIRE WRITTEN INFORMED CONSENT PRIOR TO PARTICIPATION IN THIS RESEARCH STUDY SO THAT I CAN KNOW THE NATURE AND THE RISKS OF MY PARTICIPATION AND CAN DECIDE TO PARTICIPATE OR NOT PARTICIPATE IN A FREE AND INFORMED MANNER.

PURPOSE

I am being invited to voluntarily participate in the above-titled research project. The purpose of this project is to compare patients' self-assessments of symptom distress with their assigned nurses' assessments of symptom distress.

SELECTION CRITERIA

I am being invited to participate because I am an adult who understands English and I am hospitalized for treatment related to my cancer. Approximately 30 patients will be enrolled in this study.

PROCEDURE

If I agree to participate, I will be asked to agree to completion of a questionnaire which asks about any discomfort I may be experiencing from certain symptoms. The questionnaire will take about 10-15 minutes of my time. My chart will also be reviewed to obtain information about my cancer and its treatment.

RISKS

There are no known risks.

BENEFITS

I will not be paid for my participation. However, I will be provided an opportunity to openly discuss my feelings of symptom distress.

CONFIDENTIALITY

I will be assigned an identification number which will be written on my questionnaire. The questionnaires will be reviewed by the investigator (Rhonda Davis, RN) and her thesis committee [Alice Longman, Ed. D., Ida (Ki) Moore, DNS., and Carrie Braden, PhD.].

PARTICIPATION COSTS

Cost of participation consists of the time, approximately 10-15 minutes, required to complete the questionnaire.

AUTHORIZATION

BEFORE GIVING MY CONSENT BY SIGNING THIS FORM, THE METHODS, INCONVENIENCES, RISKS, AND BENEFITS HAVE BEEN EXPLAINED TO ME AND MY QUESTIONS HAVE BEEN ANSWERED. I UNDERSTAND THAT I MAY ASK QUESTIONS AT ANY TIME AND THAT I AM FREE TO WITHDRAW FROM THE PROJECT AT ANY TIME WITHOUT CAUSING BAD FEELINGS OR AFFECTING MY MEDICAL CARE. MY PARTICIPATION IN THIS PROJECT MAY BE ENDED BY THE INVESTIGATOR OR BY THE SPONSOR FOR REASONS THAT WOULD BE EXPLAINED. NEW INFORMATION DEVELOPED DURING THE COURSE OF THIS STUDY WHICH MAY AFFECT MY WILLINGNESS TO CONTINUE IN THIS RESEARCH PROJECT WILL BE GIVEN TO ME AS IT BECOMES AVAILABLE. I UNDERSTAND THAT THIS CONSENT FORM WILL BE FILED IN AN AREA DESIGNATED BY THE HUMAN SUBJECTS COMMITTEE WITH ACCESS RESTRICTED TO THE PRINCIPAL INVESTIGATOR, Rhonda L. Davis, RN, OR AUTHORIZED REPRESENTATIVE OF THE Thesis Committee of the College Of Nursing. I UNDERSTAND THAT I DO NOT GIVE UP ANY OF MY LEGAL RIGHTS BY SIGNING THIS FORM. A COPY OF THIS SIGNED CONSENT FORM WILL BE GIVEN TO ME.

Subject's Signature

Date

INVESTIGATOR'S AFFIDAVIT

I have carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who is signing this consent form understands clearly the nature, demands, benefits, and risks involved in his/her participation and his/her signature is legally valid. A medical problem or language or educational barrier has not precluded this understanding.

Signature of Investigator

Date

APPENDIX C

NURSE DISCLAIMER FORM

SUBJECT DISCLAIMER

TITLE: Nurses' and Cancer Patients' Perceptions of Symptom Distress--A Replication Study

You are invited to voluntarily participate in a study comparing patients' self-assessment of symptom distress and nurses' perceptions of that symptom distress. By responding to items on the questionnaire, you will be giving your consent to participate.

Completion of the questionnaire will take place in an area convenient to you on your assigned hospital unit. It takes approximately 10-15 minutes. Your identity will not be revealed and your confidentiality will be maintained in all reports of this project.

You may choose not to answer some or all of the questions. Your questions will be answered and you may withdraw from the study at any time with no consequences whatsoever. Although there may not be any direct benefits to you, there are no known risks to you.

This study is being conducted as part of my work at the University of Arizona College of Nursing. If you choose to participate, your assistance is appreciated. If you choose to withdraw from the study, your decision will be respected.

Rhonda L. Davis, BSN, RN
Graduate Student
College of Nursing
University of Arizona
Tucson, Arizona 85721
296-2271

APPENDIX D

PATIENT DEMOGRAPHIC DATA FORM

Subject No. _____

Patient Demographic Data Form

1. Age: _____
2. Sex (circle one): M F
3. Ethnic group: Caucasian _____
Hispanic _____
Mexican-American _____
Black _____
Other _____
4. Employment status: Full time _____
Part time _____
Unemployed _____
Retired _____
5. Primary diagnosis: _____
6. Date of initial diagnosis: _____
7. Stage of disease: _____
8. Past cancer-related therapies: _____

9. Current cancer-related therapy: _____

10. Other illnesses: _____
11. Reason for hospitalization: _____
12. Day of hospitalization: _____
13. Number of past hospitalizations: _____

APPENDIX E

NURSE DEMOGRAPHIC DATA FORM

Subject No. _____

Nurse Demographic Data Form

1. Age: _____
2. Sex (circle one): M ☐ F ☐
3. Ethnic group: Caucasian _____
Hispanic _____
Mexican-American _____
Black _____
Other _____
4. Employment status: Full time _____
Part time _____
5. Job title: _____
6. Highest degree/diploma held:
Diploma of Nursing _____
Associate Degree of Nursing _____
Bachelor of Nursing _____
Bachelor of _____ (please specify)
Master of Nursing _____
Master of _____ (please specify)
Doctorate of Nursing _____
Doctorate of _____ (please specify)
7. Number of years professional nursing experience: _____
8. Number of years in cancer nursing: _____
9. Certification in oncology nursing (circle one): Yes ☐ No ☐
10. For how many days have you been assigned to this patient? _____

APPENDIX F

PERMISSION FOR USE OF INSTRUMENT

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6 February 1991

Mrs Davis
 Graduate Student
 College of Nursing
 University of Arizona
 3560 S Battle Place
 Tuscon
 Arizona
 85730-4401

Dear Mrs Davis


Thank you for your letter dated 31 January 1991.

We are happy to grant you permission to reproduce the Scale development by Dr Susan Holmes, which is scheduled to be published in the Journal of Advanced Nursing, Vol 16:4, subject to the usual acknowledgements of source, and on the understanding that the material in question was original when submitted to our journal.

If you wish to obtain a copy of the scale, it is best if you ask Dr Holmes for a copy of the film. She may have requested its return after publication, or you could ask Dr Holmes for an off-print of her paper when available.

I trust this information is of assistance to your enquiry, but please do not hesitate to contact me again, if you have any further queries regarding the above and I will try my best to assist.

Yours sincerely


 Julie Joyner (Mrs)
 Offprints & permissions Manager

APPENDIX G

MODIFIED SYMPTOM DISTRESS SCALE

SELF-ASSESSMENT INSTRUMENT FOR MEASURING SYMPTOM
DISTRESS

The following pages contain many different statements. Please take your time and think about what each statement says and then place a mark across the line at the point which most closely resembles how you feel today.

Index Number:

With regard to your general physical condition, please describe

***How much pain you are feeling:**

Worst pain I _____ No pain
have ever had

***How much nausea you are experiencing:**

I feel as sick _____ I do not feel
as I possibly _____ sick at all
could be

***How your appetite is:**

I cannot face _____ My appetite is
food at all normal for me

***How you sleep:**

Could not _____ Sleep is well
be worse as ever

***How mobile you are:**

Completely _____ Normal level
unable to move of physical
my body activity for me

***How your bowels are:**

a. Diarrhea

Could not _____ No diarrhea
be worse

b. Constipation

Could not _____ I am not
be worse constipated

Please continue to next page...

Page 1

***How tired you are feeling:**Could not feel
more tiredI do not feel
at all tired***Your ability to concentrate:**I cannot
concentrate
at allMy ability to
concentrate is
normal for me***How your mood is:**Could not feel
more miserableCould not feel
happier***What you are feeling about your appearance:**The worst it
has ever beenMy appearance
has not changed

***Is there any one symptom which causes you severe distress?**
If so, which one?

***Do you think the symptoms you are experiencing are caused by the
disease or the treatment?**

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